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# Glycemic Control in Pediatric Type 1 Diabetes: Role of Caregiver Literacy



**WHAT'S KNOWN ON THIS SUBJECT:** Literature indicates that literacy of caregivers/patients plays a part in the quality of care given, which in turn affects outcomes in individuals with a chronic illness.



**WHAT THIS STUDY ADDS:** This study shows that lack of basic numerical skills of caregivers has a detrimental effect on glycemic control of the child with type 1 diabetes in their care. The NVS seems to be an effective screening tool in this population.

## abstract

**OBJECTIVE:** Poorly controlled diabetes may occur because caregivers of children with type 1 diabetes fail to comprehend provided diabetes education. We hypothesized that poorly controlled diabetes is associated with lower literacy/numerical skills of caregivers of children with type 1 diabetes.

**METHODS:** Primary caregivers were evaluated by using Newest Vital Sign (NVS) and a sociodemographic questionnaire. The NVS identifies individuals who are at risk for low health literacy by measuring general literacy/numeracy skills and yields an overall estimate of health literacy. The NVS scores are interpreted to suggest inadequate, limited, or adequate literacy.

**RESULTS:** Two hundred caregivers of children who had type 1 diabetes with mean hemoglobin A1c (HbA1c) of  $8.8 \pm 1.9\%$ , age of  $11.8 \pm 3.7$  years, duration of disease of  $4.8 \pm 3.3$  years, and BMI of  $20.8 \pm 4.4$  kg/m<sup>2</sup> participated. HbA1c in those of inadequate literacy ( $10.4 \pm 2.2\%$ ) was significantly higher than in those of adequate literacy ( $8.6 \pm 1.7\%$ ;  $P < .001$ ). HbA1c in those whose caregivers had limited literacy ( $9.5 \pm 2.2\%$ ) did not differ significantly from the other 2 groups. On adjusting for independent covariates, we found that children whose caregivers had at least 50% correct math answers had better glycemic control ( $8.5 \pm 1.7\%$ ) than those who failed ( $9.8 \pm 2.1\%$ ;  $P < .0005$ ).

**CONCLUSIONS:** Literacy and numerical skills of caregivers significantly influence glycemic control of their children with type 1 diabetes. Assessing literacy/numeracy skills of caregivers and addressing these deficiencies may be crucial in optimizing glycemic control. *Pediatrics* 2010;125:e1104–e1108

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### KEY WORDS

caregivers, children, diabetes, literacy

### ABBREVIATIONS

NVS—Newest Vital Sign

HbA1c—hemoglobin A1c

This trial has been registered at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (identifier NCT00717223).

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Diabetes is a global epidemic with a prevalence of 171 million in 2000 that is projected to increase to 366 million by 2030.<sup>1</sup> Increased prevalence and a burgeoning cost of care make prudent effective communication between patients and health care providers.<sup>3</sup> This can be achieved by diabetes education, geared to empower the patient with self-management skills.<sup>4,5</sup> Patients and families are expected to understand and implement dietary changes, which includes calculating the child's insulin dose on the basis of carbohydrate counting.<sup>6</sup> Mathematic skill is required to calculate supplemental insulin to achieve glucose concentration in the target blood glucose range, but those with limited literacy are challenged by the printed word and may have difficulties with writing, speaking, listening, numeracy skills, and conceptual knowledge.<sup>7</sup> To follow dietary recommendations, it becomes important that caregivers of patients with a chronic disease such as diabetes understand nutrition labels.<sup>8</sup> In a study of 200 adult primary care patients, Rothman et al<sup>8</sup> demonstrated that poor label comprehension was highly correlated with low-level literacy and numeracy skills. These inadequacies may result in inaccuracies of carbohydrate counting and calculation of insulin doses, which may contribute to worsening glycemic control in the child.

The National Adult Literacy Survey of 1992<sup>9</sup> and the National Assessment of Adult Literacy of 2003<sup>10</sup> measured prose, document, and quantitative literacy of adults. A staggering 40 to 44 million adults in the United States have rudimentary literacy skills and are unable to understand written materials that require basic reading proficiency<sup>11</sup>; therefore, teaching and adhering to diabetes self-management is challenging for these individuals. It is unknown whether these adults are

adequately skilled to attend to the tasks required to manage a child with diabetes.

In a study of adult patients with type 2 diabetes, diabetes knowledge deficits significantly correlated with literacy and glycemic control.<sup>12</sup> Understanding literacy and its effects on diabetes management will allow for better patient education. To achieve optimal glucose control, families need to comprehend and, at a minimum, implement dietary changes, accurately calculate insulin doses, and self-administer insulin. The effect of literacy on the outcomes of chronic diseases in adults with diabetes is under investigation. In children with diabetes, despite many factors that may influence glycemic control,<sup>13–15</sup> the question of caregiver literacy on outcome of children with diabetes is scarcely reported. In this study, we hypothesized that inadequate literacy in primary caregivers would influence glycemic control of the child with diabetes for whom they care.

## METHODS

This cross-sectional study was conducted in the diabetes clinic of Texas Children's Hospital after receiving approval from the institutional review board of Baylor College of Medicine.

## Participants

Families of patients with type 1 diabetes were approached to participate during their regularly scheduled follow-up visits. Patients had to have had type 1 diabetes for at least 1 year. Caregivers spoke either English or Spanish and had no documentation of a learning disability. Participation in this study was voluntary. The health care provider discussed the study with the family and administered the Newest Vital Sign (NVS) tool to the parent/primary caregiver. The primary caregiver was asked questions regarding

annual household income and formal education. Vital signs, hemoglobin A1c (HbA1c), and information on insulin regimen were gathered from the patients' records.

## Literacy Assessment

The NVS, a bilingual (English and Spanish) screening tool, identifies patients who are at risk for low health literacy. It was validated by Weiss et al<sup>16</sup> as a suitable quick screening test for limited literacy in health care settings. This tool assesses general literacy and numeracy skills as applied to health information, yielding an overall estimate of health literacy.

The NVS is based on a nutrition label from an ice cream container. Caregivers were given the label and then asked 6 questions on interpretation and action on the information contained on the label. Caregivers retained the label so that they could refer to it while answering questions. Caregivers reviewed the label as they were asked the questions. The questions were asked orally, and the responses were recorded by a health care provider on a score sheet that contained the correct answers. On the basis of the number of correct responses, the health care provider assessed the patient's health literacy. Administration time was ~3 minutes. A score of 0 to 1 suggests a high likelihood ( $\geq 50\%$ ) of limited literacy, 2 to 3 suggests the possibility of limited literacy, and 4 to 6 almost always indicates adequate literacy.

Of the 6 questions, 4 questions tested one's basic mathematic skills. We examined the relationship of math scores with HbA1c with cutoffs at 4 of 4 correct answers and at  $\geq 3$  correct answers.

Annual household income was grouped on the basis of the US Census Bureau of 2006 as follows: less than \$22 500, between \$22 500 and \$77 500, and more than \$77 500. The highest level of

education completed by the primary caregiver was classified as well-educated (obtained a bachelor's degree or higher), moderately educated (obtained a high school diploma or general equivalency diploma or attended 1 year of college or received some specialized training), or poorly educated (completed grade 11 or less).

Statistical Analysis

Multivariate analysis was conducted to study the relationship between literacy of caregiver and glycemic control of the child with HbA1c as the dependent variable and literacy, race, language, income, and education as independent variables. This model was also tested for interactions between literacy and these confounders. A backward stepwise elimination technique (manually controlled) was used to remove interactions sequentially, beginning with the most insignificant, until all insignificant factors were removed. Estimated marginal HbA1c means were obtained for the literacy groups, with Bonferroni adjustment of confidence interval posttest. In the same manner, another model was used to test for the relationship between math skills and HbA1c. Analysis of variance with Tukey's posthoc was used to determine the difference in the means of HbA1c, age, duration of disease, and BMI among the 3 literacy groups. The data are expressed as means ± SD unless otherwise indicated. Significance was considered at  $P < .05$ . Data were analyzed by using the advanced model of SPSS 17.0 (SPSS Inc, Chicago, IL). Figures were obtained using GraphPad Prism 5 (GraphPad, San Diego, CA).

RESULTS

Two hundred families with children who had type 1 diabetes volunteered to participate in this study. Of this cohort of 106 girls and 94 boys, 180 families were fluent in the English language

TABLE 1 Sample Distribution Among the Literacy Groups (N = 200)

Parameter	Literacy		
	Limited	Possibly Limited	Adequate
Patient gender			
Female (53.0%)	3.5	6.5	43.0
Male (47.0%)	4.0	3.5	39.5
Race			
White (62.5%)	1.5	1.5	59.5
Black (18.0%)	3.5	4.0	10.5
Hispanic (17.0%)	2.5	4.5	10.0
Other (2.5%)	0.0	0.0	2.5
Language			
English (90.0%)	5.5	7.0	77.5
Spanish (10.0%)	2.0	3.0	5.0
Insulin regimen			
IIM (54.0%)	4.5	5.5	44.0
Insulin pump (26.5%)	0.5	0.0	26.0
Income			
<\$22 500 (20.4%)	2.9	5.3	12.3
\$22 500–\$77 500 (28.0%)	1.2	2.3	24.6
>\$77 500 (51.6%)	1.8	1.8	48.0
Education			
Bachelor's degree or higher (45.6%)	0.0	1.7	43.9
HSD, GED, specialized training (41.6%)	3.9	3.3	34.4
≤Grade 11 (12.8%)	2.2	5.0	5.6

IIM indicates intensive insulin management, HSD, high school diploma, GED, general equivalency diploma.

TABLE 2 Mean Characteristics of the Children With Type 1 Diabetes Within the Literacy Groups

Characteristic	Literacy			Between Groups, <i>P</i>
	Limited ( <i>n</i> = 15)	Possibly Limited ( <i>n</i> = 20)	Adequate ( <i>n</i> = 165)	
HbA1c (%)	10.4 ± 2.2	9.5 ± 2.2	8.6 ± 1.7	<.0005
Age, y	11.5 ± 4.1	12.0 ± 3.8	11.8 ± 3.7	<.9500
Duration, y	4.3 ± 3.5	4.3 ± 3.2	4.9 ± 3.3	<.6400
BMI (kg/m <sup>2</sup> )	22.0 ± 4.6	21.0 ± 4.3	21.0 ± 4.5	<.5900

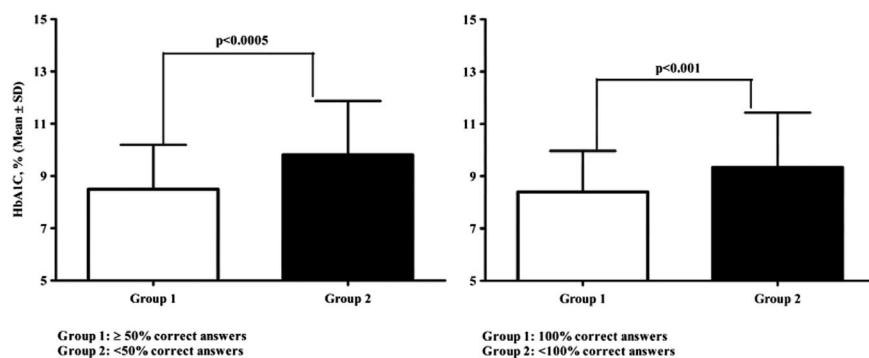
Data are means ± SD. Comparing HbA1c between the individual literacy groups shows limited versus adequate at  $P < .001$ , limited versus possibly limited at  $P < .1$ , and possibly limited versus adequate at  $P < .3$ .

and 20 communicated in Spanish only. This cohort was characterized by the mean HbA1c of  $8.8 \pm 1.9\%$ , age of  $11.8 \pm 3.7$  years, duration of disease of  $4.8 \pm 3.3$  years, and BMI of  $20.8 \pm 4.4$  kg/m<sup>2</sup>. Table 1 presents the sociodemographic distribution (as a percentage of the total) and Table 2 the mean characteristics of the cohort across the 3 literacy groups.

A significant relationship was seen between the level of literacy and HbA1c. When math scores were examined separately, a significant relationship emerged between math skills and glycemic control (Fig 1). Controlling for race, language, income, and education, multivariate analysis revealed

that literacy was related to glycemic control ( $P < .004$ ,  $R^2 = 0.23$ ), and no interaction with confounders was noted. In a separate multivariate analysis, math skills had a significant effect on glycemic control ( $P < .02$ ,  $R^2 = 0.25$ ); however, on controlling for independent confounders, a significant interaction between math and income ( $P < .01$ ) was found.

Twenty-nine (14.5%) caregivers did not disclose their annual household income. Of those who did, 20.5% were in the lowest income bracket, 28.1% were in the intermediate bracket, and 51.5% were in the highest income group. HbA1c was significantly lower in those with moderate versus low income



**FIGURE 1**

Bar graph of math skills versus glycemic control.

( $8.8 \pm 1.5\%$  vs  $9.8 \pm 2.3\%$ ;  $P < .02$ ). The difference in HbA1c between the high and low income groups was significant at  $8.3 \pm 1.6\%$  vs  $9.8 \pm 2.3\%$  ( $P < .0005$ ). Glycemic control of the moderate- and high-income groups did not differ significantly ( $P < .3$ ).

Twenty (10%) caregivers chose not to state the level of formal education completed. Of the others, 12.8% were poorly educated, 41.7% were moderately schooled, and 45.6% had received a bachelor's degree or higher. Glycemic control in the children of degree holders was  $8.4 \pm 1.7\%$ , which was significantly lower than that of children of those with moderate education ( $9.1 \pm 2\%$ ;  $P < .03$ ) and of that of children of those with poor education ( $9.5 \pm 1.9\%$ ;  $P < .02$ ). Glycemic control was similar between the moderately and poorly educated families ( $P < .7$ ).

## DISCUSSION

Ross et al<sup>17</sup> demonstrated that parental intelligence seemed to influence glycemic control significantly in a child with type 1 diabetes as opposed to child's test scores. With this study, we continue to examine the relationship between the literacy/numeracy skills of the primary caregiver and the glycemic control of children with type 1 diabetes for whom they care. Our study suggests that literacy of caregivers seems to affect significantly the glycemic control of children with diabetes.

This is probably because of the role that literacy plays in learning diabetes self-management. Moreover, this study suggests that literacy is associated with better glycemic control. A previous study demonstrated that greater diabetes knowledge of caregivers is associated with better glycemic control.<sup>18</sup> Hence, assessing literacy of caregivers at onset may allow for targeted improvement in glycemic control by use of grade-appropriate material and language by diabetes educators and health care providers.<sup>19</sup>

Arithmetic is an integral part of literacy.<sup>20</sup> Diabetes management requires basic mathematic skills. Inability of caregivers to subtract and add accurately and understand percentages limits their ability to count carbohydrates and calculate optimal insulin doses accurately. Evaluation of responses that required basic mathematic skills revealed a significant association between low skills and poorer glycemic control. In this assessment, we were limited by the inability to separate language inadequacies from purely math skill deficiencies because the mathematic questions in the NVS are wordy and not yet validated separately for math skills. Because of the simplicity of the test, it can be used as a rapid screening tool to establish deficits; therefore, math questions were examined separately. A recent study of

adult patients with diabetes concluded that poor numeracy skills were common in these patients.<sup>21</sup> An additional inference of that study was that deficient diabetes-related numeracy skills were associated with worse perceived self-efficacy, fewer self-management behaviors, and possibly poorer glycemic control.<sup>21</sup> The performance of the caregivers in our study may be reflective of previous findings that the participating adults, even highly educated ones, had difficulty with relatively simple numeracy questions.<sup>22</sup> This further reinforces the need to assess caregivers' literacy and numeracy skills before making dietary recommendations<sup>8</sup> and using grade appropriate diabetes education material.<sup>19</sup>

The limitations of this study are that it was a single-site study and that the ethnic distribution was neither equal nor representative. Other unequal distributions were present among the education and income groups. We also had far fewer Spanish- than English-speaking participants. The unequal ethnic participation is representative of the population seen at our center, which results in far fewer Spanish than English speakers. Furthermore, those who are less educated and of lower income are less likely to access outpatient health care.<sup>23</sup> The voluntary nature of this study may have precluded participation of the less literate individuals, who often harbor a deep sense of shame over their reading inadequacies.<sup>23</sup> We did not assess family structure and its impact on glycemic control, but it is well established that children of 2-parent families have significantly better glycemic control than those of a single-parent home.<sup>18,24</sup>

Varying degrees of interactions between literacy, income, and education contributed to glycemic control. A significant and independent relationship between literacy and glycemic control



was seen after controlling for these interactions, yet we cannot overlook that limited literacy is associated with being poor, having had less formal education, and belonging to a minority ra-

cial or ethnic group.<sup>9</sup> The onus lies with the providers and educators to be cognizant of these effects. It may be prudent to establish the literacy and numeracy skills of primary caregivers of

children with type 1 diabetes so that culture-appropriate measures<sup>25</sup> can be taken to maximize the benefits of diabetes education if optimal glycemic control is to be achieved.

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